

Consent Policy Design Group

Meeting Minutes

MEETING DATE	MEETING TIME	Location
June 4, 2019	1:00PM – 2:00PM	Join Zoom Meeting: https://zoom.us/j/269726549 Dial: +1 646 876 9923 US Meeting ID: 269 726 549

DESIGN GROUP MEMBERS					
Stacy Beck, RN, BSN		Susan Israel, MD	x	Nic Scibelli, MSW	x
Pat Checko, DrPH	x	Rob Rioux, MA			
Carrie Grey, MSIA	x	Rachel Rudnick, JD			
SUPPORTING LEADERSHIP					
Allan Hackney, OHS	x	Chris Robinson, CedarBridge	x	Tim Pletcher, Velatura	
Carol Robinson, CedarBridge	x	Ross Martin, CedarBridge	x	Lisa Moon, Velatura	x
Michael Matthews, CedarBridge	x	Sheetal Shah, CedarBridge	x	Sabina Sitaru, HIE Entity	x

Minutes			
	Topic	Responsible Party	Time
1.	Welcome and Overview	Michael Matthews	1:00 PM
	Michael Matthews welcomed the workgroup members and provided an overview of the agenda.		
2.	Public Comment	Attendees	1:02 PM
	There was no public comment.		
3.	Summary of Group Member Comments	Attendees	1:05 PM
	<p>Michael introduced the next agenda item and provided an overview of questions and comments that have been received from Design Group members thus far. There have been a few questions asked regarding data that is reported to the state, as well as what happens to the Design Group recommendations when they are delivered to the Health IT Advisory Council. Michael explained that we will continue to keep these questions in mind as we explore the initial use cases and the associated consent policy. We will make sure we are capturing Design Group member comments and thoughts as we move through the process.</p>		
4.	Roadmap to Final Consent Recommendations	Velatura	1:15 PM
	<p>Ross Martin introduced the next agenda item and provided an overview of the Consent Policy Design Group process review, which is visually depicted on slide 10. The diagram provides an overview of the scope of the Design Group’s work. The items in yellow are the responsibility of the Design Group; the light yellow items are in-progress, and the dark yellow items are completed. The green items are the responsibility of other workstreams; the light green items are in-progress and the dark green items are completed.</p> <p>Pat Checko asked if we are talking about what it will take in order to address the initial identity mapping use case and address one specific use case, rather than getting lost in the weed of all of the possibilities. Michael said that this is correct and that the identity and care mapping use case will be the initial use case coming out of the HIE and will be foundational to other use cases.</p> <p>Susan Israel says she is not totally clear about what we is in-scope and out-of-scope for the Design Group. Susan said on slide 26, there is information about patients providing consent about their participation in the HIE and asked if we are going to address this topic. Susan asked what “participation” means exactly and if this applies to the identity and care mapping use case or excluding entire records from the HIE. Ross said that today we are focused on the identity and care map use case, because it is foundational to the HIE and its future use cases. Ross said we are focused only on the disclosure part of the use case today, and in future</p>		

Prepared By: CedarBridge Group

conversations we will discuss any additional need for explicit and managed consent. Ross said one thing to understand around notice and disclosure in today’s context, is that this is not direct consent; it is saying that be virtue of receiving care from a provider who participates in the HIE, you are consenting to receive care and for participation in the HIE on this specific use case. Susan asked for clarification. Ross said that the act of disclosure, and the notice of privacy practices around what the provider is doing with information, and the patient acknowledgment of this information, means that the patient is consenting to both receive care and to the disclosure of their information by virtue of the care relationship that they are entering into. Susan said that currently, individuals are not required to sign these HIPAA forms when they visit a provider. Susan asked if individuals will be asked to consent to disclosure of information by agreeing to receive care from a given provider. Ross said that at a baseline, this is true, and this is what we will be focused on today. For certain use cases, in the future, additional consent can be layered on top of this process where individuals will have the opportunity to opt-out of certain use cases. This could be managed by the provider or the HIE. Susan said that the discussion of consent has been kicked down the road for a long period of time, and it is her perception that the HIE has contracted for a system that will allow records to be sent to the HIE without direct patient consent, particularly for state-mandated information.

Susan asked if patients can consent to have the list of their providers put into the HIE. Susan asked for clarification on disclosure and if there will be any additional consent up-front. Pat suggested that we move forward, as these topics will be addressed by the presentation. Ross said that Susan keeps using the term “consent” in a very specific fashion, where a patient specifically agrees to have their information added to the HIE, however consent can happen many different ways, including through HIPAA treatment, payment, and healthcare operations. Patients can consent to the effective management and sharing of their information in order for their provider to deliver appropriate healthcare services. Ross said that the disclosure we will be talking about today is the lowest common denominator and will make sure there is this baseline consent, if patients agree to receive care. Ross said that in some cases, regardless of the mode for information sharing, the only way to prevent some information to be shared, is to not receive care. Susan asked if there are any states that allow patients to opt-out of their medical records being shared via the HIE. Ross said that is not what he is saying and that today all we are doing today is establishing a baseline for the foundation for this one specific use case. In two weeks, we will discuss for what instances, or use cases, it would be appropriate to have additional levels of consent. Ross said that this Design Group might determine that they want to recommend an opt-out opportunity for every use case, or the Design Group may say that this opportunity should only be available for certain use cases, but for every use case there needs to be a mechanism to disclose these practices and opportunities. This is all we are talking about today and it is only applicable to the first use case at this point. These recommendations will go from this group to the Health IT Advisory Council, where it will be packaged with the other relevant work and packaged to the HIE entity. Susan asked if patients will have the opportunity to opt out of the identity and care mapping use case, and exclude this information from the HIE, or will this be automatically included. Michael said that this decision has not been made, as has been stated previously, and the point of this Design Group is to make recommendations that will be thoughtfully considered by the HIE entity as it is making final determinations. Michael said there is not a set of decisions or structures that are already in place that are being shared with the group; we are sharing the initial use case and offering an approach that will drive consent based on HIPAA TPO and notifications. This is not a decision; it is a starting place for today’s discussion. It is up to the Design Group what they want to recommend. Michael suggested that we move the discussion forward into the next agenda items.

5.	Patient and Provider Identity Care Map Core Function	Dr. Ross Martin	1:20 PM
<p>Ross introduced the next agenda item, relating to the patient and provider identity care map core function. Ross explained slide 12, regarding the consent balancing act. Next, Ross explained the core tasks for today, including the task of outlining content of the consent policy for Notice of Privacy Practices Disclosure related to the patient and provider identity and care map core HIE use case, and the relevant components of this policy.</p>			

Next, Ross provided an overview of the HIPAA organizing principle for data sharing, explaining that Covered Entities with relationships in common may share individually identifiable health information for the purposes of treatment, payment, and healthcare operations. Ross explained that identity and care maps identify the providers actively caring for a patient as well as the payers covering the costs of the patient's care to coordinate all the patient's electronic health information. Ross explained that the identity and care maps let providers declare active care relationships with patients, they allow for information to be actively routed to providers in active care relationships with patients, they enable updates to the entire care team in real time, and they enable easy views of care team members by authorized participants. Ross explained that this use case will be the foundation for the other services that the HIE could provide in the future.

Next, Ross provided an overview of the example disclosure notification policy, as outlined on slide 22. Ross asked if any Design Group members would like to suggest any changes to the proposed language or add any additional comments. There were no additions from Design Group members.

On slides 23 and 24, Ross outlined the questions for discussion regarding the responsibilities of the HIE entity for the proposed disclosure notification policy. These questions include:

- Should the HIE entity provide content and material to all HIE participants to support patient identification?
- Should the HIE entity provide sample language for inclusion in participants' Notice of Privacy Practices?
- Should the HIE entity provide PDFs and print materials at a suitable reading level that provide information for patients about the HIE and its basic services along with links to more on-line patient information?
- Should there be any recommendations related to language support / translation services?
- Should there be references to relevant regulation, access to consent, and participations documents, etc.?
- Should the HIE entity publish a continuously updated list of all participating organizations and the use cases in which they are participating? At what level of granularity?
- Should the HIE entity create and maintain a method for patients to sign up to receive regular updates on HIE policies, use cases, and participants?

Ross asked the Design Group if there are thoughts on the listed questions, or if there are other questions that should be considered.

Nic Scibelli said that it would be helpful for the entity to provide supporting materials to the participating organizations. Ultimately, the process of providing the actual materials will be the responsibility of the participating organizations, because this is the way it has always been done, but it would be helpful for the HIE entity to provide sample language and documents to be incorporated and utilized.

Nic said that there should also be a place that anyone can go to and see a fair amount of detail and granularity regarding who is participating, what the use cases are, etc. Whether this is a website, or information provided by participating organization to patients and consumers, there should be a fair amount of granularity and as much transparency as possible. Sabina Sitaru, of the HIE entity, said that they are in the process of looking at these items for developing the HIE website, and they appreciate the guidance and recommendations. Susan Israel said that she agrees there should be a website that provides information to the public so that it is not dependent on each provider to distribute this information. Susan supports as much transparency as possible. Susan said that the word "privacy" misleads the public and she would prefer the word "confidentiality." Pat agrees that there needs to be a public-facing website. Pat said she is not sure who should operate this website. Pat said that if there is an intent down-the-road to have a public-facing website where OHS posts various reports, this may be an appropriate location to house this information.

Pat said that her question, as a patient looking at this process, is if she will receive this information each time she visits one of her providers. Ross said that these are some of the questions we want to explore, including frequency of updates. It is his understanding that each provider would need to provide information disclosing their participation and how the information will be used. In Connecticut, with the use case model, it will be important for patients to understand what their provider is actively participating in, because there could be a wide range of participation levels amongst providers. Pat said that whatever is written for a patient needs to be at a level that is understandable and at an appropriate reading level. Michael agreed and said that this has always been a challenge for these notices. Michael said that in this case, this information and policies would be available from the HIE entity's website.

Ross asked the Design Group about the use of the word "privacy" and said that the term "Notice of Privacy Practices" is a term defined by HIPAA and cannot be altered. Nic said that if this impacts the paper work burden, he would recommend not making it separate and would recommend a lengthy annual review with clinical and legal staff to make sure it is appropriate. Nic said it make sense to use content and suggested language, but to leave the implementation and distribution to the participating organizations. Pat said that the public does not necessarily understand the differentiation between the words "privacy" and "confidentiality" and there could be ways to address this in understandable language. We can discuss the wording at a later point in time. Ross said we are not asking the group to recommend specific language at this time, rather we are creating recommendations for the guiding principle and the HIE entity will handle the finalization.

Pat asked what is done currently regarding language support and translation services. Michael said we can determine the actual requirement around this as a follow-up item.

6.	Wrap-up and meeting Adjournment	Michael Matthews	2:00 PM
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Michael Matthews thanked everyone for a very productive and engaging conversation. Michael said as a follow-up we will craft a straw-person proposed approach, based on today's discussion and directional input, and will distribute this to the group in advance of the next meeting. Michael said that we will review this at the next meeting and will continue to move the process forward. Michael outlined the process for the group to provide comments via email between meetings.

The meeting was adjourned.

Upcoming Meeting Schedule: June 18, 2019; July 9, 2019; July 23, 2019